

SUPPORTING THE GOALS AND IDEALS OF NATIONAL CYSTIC FIBROSIS AWARENESS MONTH

Mr. STEARNS. Madam Speaker, I move to suspend the rules and agree to the concurrent resolution (H. Con. Res. 357) supporting the goals and ideals of National Cystic Fibrosis Awareness Month.

The Clerk read as follows:

H. CON. RES. 357

Whereas cystic fibrosis is one of the most common life-threatening genetic diseases in the United States and one for which there is no known cure;

Whereas the average life expectancy of an individual with cystic fibrosis is 35 years, an improvement from a life expectancy of 10 years in the 1960s, but still unacceptably short;

Whereas approximately 30,000 people in the United States have cystic fibrosis, more than half of them children;

Whereas one of every 3,500 babies born in the United States is born with cystic fibrosis;

Whereas more than 10,000,000 Americans are unknowing, symptom-free carriers of the cystic fibrosis gene;

Whereas the Centers for Disease Control and Prevention recommends that all States consider newborn screening for cystic fibrosis;

Whereas the Cystic Fibrosis Foundation urges all States to implement newborn screening for cystic fibrosis to facilitate early diagnosis and treatment which improves health and longevity;

Whereas prompt, aggressive treatment of the symptoms of cystic fibrosis can extend the lives of people who have the disease;

Whereas recent advances in cystic fibrosis research have produced promising leads in gene, protein, and drug therapies beneficial to people who have the disease;

Whereas innovative research is progressing faster and is being conducted more aggressively than ever before, due, in part, to the Cystic Fibrosis Foundation's establishment of a model clinical trials network;

Whereas although the Cystic Fibrosis Foundation continues to fund a research pipeline for more than two dozen potential therapies and funds a nationwide network of care centers that extend the length and quality of life for people with cystic fibrosis, lives continue to be lost to this disease every day;

Whereas education of the public about cystic fibrosis, including the symptoms of the disease, increases knowledge and understanding of cystic fibrosis and promotes early diagnosis; and

Whereas the Cystic Fibrosis Foundation will conduct activities to honor National Cystic Fibrosis Awareness Month in May, 2006: Now, therefore, be it

Resolved by the House of Representatives (the Senate concurring), That the Congress—

(1) honors the goals and ideals of National Cystic Fibrosis Awareness Month;

(2) promotes further public awareness and understanding of cystic fibrosis;

(3) advocates for increased support for people who have cystic fibrosis and their families;

(4) encourages early diagnosis and access to quality care for people with cystic fibrosis to improve the quality of their lives; and

(5) supports research to find a cure for cystic fibrosis by fostering an enhanced research program through a strong Federal commitment and expanded public-private partnerships.

The SPEAKER pro tempore. Pursuant to the rule, the gentleman from

Florida (Mr. STEARNS) and the gentleman from Massachusetts (Mr. MARKEY) each will control 20 minutes.

The Chair recognizes the gentleman from Florida.

GENERAL LEAVE

Mr. STEARNS. Madam Speaker, I ask unanimous consent that all Members may have 5 legislative days within which to revise and extend their remarks and insert extraneous material on this resolution.

The SPEAKER pro tempore. Is there objection to the request of the gentleman from Florida?

There was no objection.

Mr. STEARNS. Madam Speaker, I yield myself such time as I may consume.

Madam Speaker, I rise today in support of H. Con. Res. 357, which supports the goals and ideals of National Cystic Fibrosis Awareness Month, beginning in May. Every year in the United States, about 1,000 children are born with cystic fibrosis, or CF, a life-shortening genetic disease.

According to the Cystic Fibrosis Foundation, those children face a median life expectancy of 36 years, an average that, fortunately, has continued to increase as science and research have developed better treatment and drugs. And while a median life expectancy of 36 is unacceptably low, that figure is cause for hope for those living with the disease and, of course, their families. They know that in 1955, the year parents of children suffering from this disease formed the Cystic Fibrosis Foundation, children born with CF usually did not live to attend preschool. As the life expectancy increases, those suffering with this disease and their families continue to work for a cure or a life-extending treatment.

Madam Speaker, while a cure for cystic fibrosis remains illusive, the symptoms and effects of the disease are fairly simple. CF is one of the most common life-threatening genetic diseases in the United States. More than 30,000 people in the United States have CF, and over half of them are children.

In addition, over 10 million Americans are unknowing, symptom-free carriers of the cystic fibrosis gene. Cystic fibrosis affects the lungs and digestive system.

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The defective gene that causes CF triggers the production of abnormally thick mucus in the lungs that leads to restricted breathing, recurring lung infections, and in many cases digestive problems. The infections deteriorate the lungs and their capacity to deliver oxygen to the body, a condition that worsens over time and in many cases even leads to death or the need for a lung transplant. One of the goals of H. Con. Res. 357 is to promote the need for early diagnosis and the importance of newborn screening so that treatment of children with CF can begin as soon as possible to improve their health and longevity.

The five decades that have passed since the founding of the Cystic Fibrosis Foundation have brought not only hope but years to the lives of those suffering from CF. The Cystic Fibrosis Foundation continues to be at the forefront of making more with less in the area of drug discovery and development. The Therapeutics Development Program, TDP, created and launched by the CF Foundation, has pioneered new ways to conduct cutting-edge, life-saving research in a cost-effective and efficient manner. This program now includes 18 major research institutions across the country in an established clinical trials network. The TDP provides innovative companies with funding, raised through private donations to the CF Foundation, to undertake research and development on promising new drug candidates, and supports an extensive pipeline of potential new therapies. In fact, the CF Foundation currently has more than 30 drugs and therapies in various stages of clinical trials, any one of which could dramatically improve the life of someone suffering from CF. I believe that the innovative programs like the Therapeutics Development Program are part of the blueprint for more efficient and cost-effective health care and should be supported. So, as you can see, Madam Speaker, CF Foundation-sponsored research is adding precious years to the lives of those living with the disease so that they might live long enough to benefit once a cure is found.

Today there is more potential research on new drugs and therapies than funds to finance that lifesaving work. This is a problem created by a wealth of scientific riches, and one that I hope can be bridged by more public-private partnerships which leverage our world-class biotech and pharmaceutical companies with the capabilities of institutions like the National Institutes of Health to ensure that the discovery phase of identifying new drugs and compounds to treat cystic fibrosis continues. To that end the resolution before us today advocates strong partnerships between government resources like the NIH and nonprofits like the Cystic Fibrosis Foundation as a key means to improve care for those with "orphan" diseases like CF.

Madam Speaker, in closing, I would like to commend my friend and colleague Mr. MARKEY from Massachusetts for his leadership and work supporting this resolution and for our partnership cochairing a new Congressional Cystic Fibrosis Caucus. The Congressional Cystic Fibrosis Caucus, like this resolution, is intended to provide Members and the American public a better understanding of cystic fibrosis and the need to support the incredible work that is being done by the Cystic Fibrosis Foundation as well as through public-private collaboration to find a cure.

I would also like to thank all those Members on both sides of the aisle who have cosponsored H. Con. Res. 357 and

those who have joined the Congressional Cystic Fibrosis Caucus. And anyone who is watching is welcome to call my office or Mr. MARKEY's office. We would like to have your support, and we look forward to it.

So, my colleagues, please join me in honoring and supporting the goals and ideals of National Cystic Fibrosis Awareness Month by simply agreeing to H. Con. Res. 357.

Madam Speaker, I reserve the balance of my time.

ANNOUNCEMENT BY THE SPEAKER PRO TEMPORE

The SPEAKER pro tempore (Mrs. DRAKE). Members should direct their comments to the Chair and not to the television audience.

Mr. MARKEY. Madam Speaker, I yield myself such time as I may consume.

I thank my friend from Florida Mr. STEARNS. He and I have partnered on the resolution and on cofounding the Congressional Cystic Fibrosis Caucus. And I want to thank him for his commitment to CF, its cause, and the difference that this institution can make in helping to find the cure. It is, without question, something that we can agree upon on a bipartisan basis.

The resolution before us today is to support the goals and the ideals of the National Cystic Fibrosis Awareness Month, and it is really so that we can bring the most powerful four-letter word to this cause, and that word is "hope"; hope that the United States Government will increase its funding, will help to find the cure for this dreaded disease, that we can give hope to the families who are affected by it. And today is a really important day on that path because for the first time we do have a caucus, and this resolution in a lot of ways will memorialize that and give more momentum to finding the cure.

CF is one of the most common life-threatening genetic diseases in the United States. People with CF produce abnormally thick, sticky mucus, which makes breathing very difficult. They find, as a result, they cough and they wheeze constantly and are at constant risk for life-threatening lung infections.

Approximately 30,000 children and adults in the United States have cystic fibrosis, but it affects far more than those 30,000 people. It affects all of the families and the loved ones of those people who are struggling with this horrible disease. It affects the moms who have to wake up at 5 a.m. so that they can pound on their child's chest before they go to work. It affects their siblings who have to wait with their sister while she goes to yet another doctor's appointment. And it affects the dads who worry that their child will never grow up to have a normal life. This resolution is about supporting these families and providing them with the hope for a better future.

Significant improvements have been made in the treatment of cystic fibrosis. A few decades ago many children

with CF did not live past 10 years of age. Today life expectancy is 35 years of age, and much of these achievements are due to the hard work and the dedication of the Cystic Fibrosis Foundation. That is why CFF really stands for courageous fighting families, courageous fighting friends of those families.

Yet even with this incredible work of our courageous fighting families, we still have a long way to go to provide the people with CF with a normal and healthy life. It is time for Congress to become more involved in the pursuit of a cure. We need to make a greater investment in research and make a stronger commitment to the people with CF, their families, and their caretakers.

This is something which in the 21st century we should leave as a forgotten memory, but we can only do it if we provide hope now. It is the most powerful word in the English language: Hope that we can raise awareness of the families struggling with CF, hope that we can find better treatments and ultimately a cure, hope that our children will have to turn to the history books to find that there ever was such a thing as cystic fibrosis.

I thank, again, the cochair of the caucus Mr. STEARNS. This is now going to bring a larger, more powerful spotlight on this disease. And hopefully, working together in a bipartisan fashion, we can address this as a human issue and not as a Democrat or Republican issue.

Mr. MCGOVERN. Madam Speaker, I rise in support of H. Con. Res. 357, offered by the distinguished gentleman from Florida (Mr. STEARNS). This resolution would support the goals and ideals of National Cystic Fibrosis Awareness Month.

Cystic Fibrosis is one of the most common life-threatening genetic diseases in the United States. Approximately 30,000 people in the United States have cystic fibrosis, and about 1,000 new cases of cystic fibrosis are diagnosed each year. Tragically, more than half of those with CF are children. As I stand here today, more than 10 million Americans are unknowing, symptom-free carriers of the cystic fibrosis gene.

Significant improvements have been made in the treatment of cystic fibrosis. Just a few decades ago, children with CF did not live past 10 years of age. Today the life expectancy has improved, and the number of adults with CF has steadily grown. Even so, there is no cure for this disease, and much still must be done to provide people with CF with a normal and healthy life expectancy.

Early diagnosis is the key, and that is why it's so important that we work to further public awareness and understanding of cystic fibrosis. We must increase support for those affected by this disease and ensure that they have access to quality care, and we also must support research to find a cure for CF.

I am proud to provide my support to this cause, and I ask my colleagues to join me in supporting H. Con. Res. 357 so that the month of May can be dedicated to educating all Americans about cystic fibrosis, about the courage of those who suffer from this disease, and about the important research underway to find a cure.

Mr. MARKEY. Madam Speaker, I yield back the balance of my time.

Mr. STEARNS. Madam Speaker, I have no further requests for time, and I yield back the balance of my time.

The SPEAKER pro tempore. The question is on the motion offered by the gentleman from Florida (Mr. STEARNS) that the House suspend the rules and agree to the concurrent resolution, H. Con. Res. 357.

The question was taken.

The SPEAKER pro tempore. In the opinion of the Chair, two-thirds of those present have voted in the affirmative.

Mr. STEARNS. Madam Speaker, on that I demand the yeas and nays.

The yeas and nays were ordered.

The SPEAKER pro tempore. Pursuant to clause 8 of rule XX and the Chair's prior announcement, further proceedings on this question will be postponed.

AUTHORIZING USE OF CAPITOL GROUNDS FOR THE GREATER WASHINGTON SOAP BOX DERBY

Mr. SHUSTER. Madam Speaker, I move to suspend the rules and agree to the concurrent resolution (H. Con. Res. 349) authorizing the use of the Capitol Grounds for the Greater Washington Soap Box Derby.

The Clerk read as follows:

H. CON. RES. 349

Resolved by the House of Representatives (the Senate concurring),

SECTION 1. AUTHORIZATION OF SOAP BOX DERBY RACES ON CAPITOL GROUNDS.

The Greater Washington Soap Box Derby Association (in this resolution referred to as the "Association") shall be permitted to sponsor a public event, soap box derby races, on the Capitol Grounds on June 17, 2006, or on such other date as the Speaker of the House of Representatives and the Committee on Rules and Administration of the Senate may jointly designate.

SEC. 2. CONDITIONS.

The event to be carried out under this resolution shall be free of admission charge to the public and arranged not to interfere with the needs of Congress, under conditions to be prescribed by the Architect of the Capitol and the Capitol Police Board; except that the Association shall assume full responsibility for all expenses and liabilities incident to all activities associated with the event.

SEC. 3. STRUCTURES AND EQUIPMENT.

For the purposes of this resolution, the Association is authorized to erect upon the Capitol Grounds, subject to the approval of the Architect of the Capitol, such stage, sound amplification devices, and other related structures and equipment as may be required for the event to be carried out under this resolution.

SEC. 4. ADDITIONAL ARRANGEMENTS.

The Architect of the Capitol and the Capitol Police Board are authorized to make any such additional arrangements that may be required to carry out the event under this resolution.

SEC. 5. ENFORCEMENT OF RESTRICTIONS.

The Capitol Police Board shall provide for enforcement of the restrictions contained in section 5104(c) of title 40, United States Code, concerning sales, advertisements, displays,